Research Involvement and Engagement

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Recognition, remuneration and reimbursement of patient and public involvement partners in pragmatic randomised controlled trials. A survey of author practices

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Abstract

Background Patient and public involvement (PPI) in the design and conduct of clinical trials has been increasingly encouraged by funders as an essential ingredient in the conduct of research. Recognition of PPI partners through acknowledgement or authorship, and financial supports, including remuneration and reimbursement, may facilitate involvement. However, little empirical data exists regarding current practices of recognising, remunerating and reimbursing PPI partners for their contributions to research.

Aims To describe the extent to which patient and public partners are recognised and remunerated for their involvement in a cohort of pragmatic randomised controlled trials (RCTs).

Methods Cross sectional survey of corresponding authors of pragmatic RCTs published between January 1, 2014, and April 3, 2019.

Results From 2585 delivered invitations, 710 responded, with 334 (47%) indicating that they had involved PPI partners within the trial. Among 300 respondents to questions about authorship, 59 (20%) reported PPI partners were included as named authors and 19 (6%) that PPI partners were included as part of a group authorship. Of 300 respondents to questions regarding remuneration, 132 (44%) indicated that PPI partners were provided some form of remuneration. Of the 303 respondents to questions about reimbursement, 186 (61%), indicated that PPI partners were reimbursed for expenses incurred. Of 274 respondents who completed all three questions regarding reimbursement, remuneration, and authorship or acknowledgment, 83 (30%) indicated that all three were provided to PPI partners, while 40 (15%) indicated that they provided none of the options.

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Conclusion A fifth of researchers reported including PPI partners as named co-authors, less than half provided remuneration, and over a third did not reimburse partners. There is a need to better understand the nature of any barriers that research teams and PPI partners face regarding recognition, reimbursement, and remuneration, and to develop targeted interventions that will address these barriers.

Plain English summary Patient and public involvement (PPI) in the design and conduct of clinical trials is encouraged or required in many cases. It is important to recognise PPI partners for their time and insight. Despite many guidelines being produced, we actually know very little about how researchers recognise and financially support PPI partners. To address this gap, we surveyed the authors of published clinical trials about their practices. Specifically, we asked researchers whether they had acknowledged their PPI partners or included them as co-authors, provided financial support for their time, or had covered expenses. From 2585 delivered invitations, a total of 710 researchers responded. Almost half (334/710, 47%) said they had involved PPI partners in their trial. A fifth of these researchers (59/300, 20%) reported that they included PPI partners as named co-authors. Just under half (132/300, 44%) reported that they had provided financial support for the time of their PPI partner. Almost two thirds (186/303, 61%) did cover expenses. Of those who completed all three questions almost a third (83/274, 30%) reported that all three options were provided to PPI partners. However, 40 (40/274, 15%) reported that they provided none of the options.

Keywords Patient and public involvement, Compensation, Survey, Questionnaire, Ethics, Authorship, Acknowledgement, Reimbursement, Remuneration

Background

Patient and public involvement (PPI) – in which there is active collaboration between researchers and patients or the public [1, 2] – in the design and conduct of clinical trials enables research that is meaningful, relevant, and important to individuals with lived experience of an illness or condition [3]. Indeed, the impact of PPI on trial design and conduct is the subject of numerous reviews [4–8] and has been shown to improve trial recruitment [7].

There is increasing awareness of the need to better understand how PPI partners are recognised and financially supported for their contributions to academic research [9, 10]. Recognition of PPI partners may include co-authorship or formal acknowledgement within manuscripts. Financial support may include remuneration (e.g. honoraria or salary) [11] or reimbursement of expenses incurred (see Table 1).

Remuneration and reimbursement may facilitate involvement by groups that face financial barriers to partnering in health research, thus enhancing equity, diversity, and inclusion regarding PPI in research [9, 10]. In a Canadian survey of over 600 patient partners in health research and care, 12% reported receiving disability and/or income replacement benefits and 43% were retired. Notably, almost one quarter of respondents indicated costs associated with being a patient partner as a barrier to engagement [15]. Consequently, it has been argued that without remuneration PPI partners would largely consist of people who have the means to allocate unpaid time and energy towards research. Therefore, not offering remuneration may exclude potential PPI partners from equity deserving groups or communities [16] (i.e. groups or communities who, because of systemic discrimination, do not have the same access to resources and opportunities available to other members of society) [15].

A recent systematic review of health studies that specifically cited the Guidance for Reporting the Involvement of Patients and the Public (GRIPP) [17] or GRIPP2 [18] reporting guidelines identified 316 studies that had actively engaged PPI partners. Of these, within 206 (65%) PPI partners were acknowledged within the manuscripts, 156 (49%) included a PPI partner as a co-author, and in 67 (21%) it was reported that PPI partners were provided reimbursement of expenses incurred. In addition, 79 studies (25%) reported that remuneration was provided [19]. Other studies have reported broadly on the prevalence of patient or public authorship in clinical trials [20, 21], child health research [22], knowledge syntheses [23], and health research more generally [24]. However, even with the social and ethical rationales, and multiple guidance documents [11, 12, 25, 26], there is a lack of research reporting on the recognition, remuneration or reimbursement of PPI partners in clinical trials.

To address this gap, we surveyed corresponding authors - identified from a cohort of pragmatic randomised controlled trials (RCTs) published between 2014 and 2019 [27] - to determine whether and how patient and public partners (PPI partners) were recognised, remunerated, and reimbursed. As opposed to early phase trials where safety and tolerability of a drug may be the focus, the results of pragmatic RCTs are intended to directly inform clinical or health policy decisions. Therefore, pragmatic RCTs should mimic as closely as possible the context of the healthcare decision [28, 29]. It is particularly important to have patient and public input in pragmatic RCTs

Table 1 Definitions of key terms

Term	Definition
Recognition	Examples might include acknowledgement or co-authorship (including group authorship) on manuscripts, or co-presenting research findings at a conference.
Remuneration	The provision of goods, services, or something of monetary value, in exchange for engagement. This may include offering payment or something of monetary value in exchange for their engagement. Examples might include honoraria, or a monetary amount based on contributed time or effort [12, 13, 14].
Reimbursement	The repayment of out-of-pocket expenses incurred. This may include travel, accommodation, parking, or child-care support necessary to enable involvement in a research activity [11].

so that the trials reflect the realities of lived experience. Specifically, we sought to answer the following questions: Among trialists that engaged PPI partners, what is the self-reported prevalence of:

1. Recognition through authorship or acknowledgement of PPI partners in the main trial report?
2. Remuneration for PPI partners?
3. Reimbursement for out-of-pocket expenses incurred by PPI partners?
4. Combinations of these forms of recognition, remuneration, and reimbursement?

Methods

Sample and sampling frame

As reported previously [27], we surveyed corresponding authors of pragmatic RCTs published between January 1, 2014, and April 3, 2019. The RCTs were identified as part of a scoping review of health-focused trials that were deemed to be pragmatic in orientation. The review identified 4337 eligible trials, with most trials published in the USA, UK, and Australia. The details of the search strategy and full results of the scoping review have been published previously [30, 31]. The survey was developed iteratively through discussion and written feedback by two PPI partners (AH, MS), trialists, and methodologists who support PPI. All team members were involved in developing the items along with wording and choice options. Our PPI partners provided insights into items and aspects of recognition, remuneration, and reimbursement that were important and relevant to PPI partners, as well as informing the choice options included within survey questions.

Subsequently we surveyed corresponding authors of these trials to better understand PPI practices. As reported elsewhere [27], we identified corresponding authors in the following countries: Canada, United States, United Kingdom, Australia and New Zealand, South Africa, France, Belgium, Denmark, Finland, Germany, Italy, the Netherlands, Norway, Spain, Sweden and Switzerland, which yielded 3501 eligible trials. As individuals could potentially be the corresponding author for multiple reports, we selected only the most recently published report. Where the corresponding authors had no email addresses listed, we used online searches to identify an email address. In three cases a corresponding author email address could not be identified. This provided a sampling frame of 3163 unique corresponding authors.

Data collection

The survey was administered using the SurveyMonkey online platform. The survey consisted of 27 open- and closed-ended items relating to PPI in the published trial. The survey included a definition of PPI and respondents were asked to indicate that they had read and understood the definition prior to completing the survey. A copy of the full survey is included as a Supplementary File S1.

The survey was piloted with a random sample of 100 corresponding authors. No substantive changes were made, and pilot data were included in the final analysis. Invitation emails sent to the corresponding authors included information about the trial for which they were being approached as well as a unique link which allowed for survey responses to be linked to trial characteristics already collected as part of the previous scoping review. All participants were prompted to review a participant information sheet at the start of the survey and were advised that completing the survey was voluntary and doing so provided implied consent to participate. Survey participants were given the option to be entered into a draw for one of five $100 CAD Amazon gift cards. Email invitations were sent on February 8, 2022, followed by up to three reminders. The survey was closed on April 5, 2022.

This paper focuses on the survey questions that pertained to PPI partner recognition (authorship or acknowledgment), remuneration, or reimbursement. Specifically, survey respondents who reported that PPI partners were involved in the trial were asked:

1. Were PPI partners acknowledged in the manuscript or elsewhere? Response options: Named as co-author(s); Included in group authorship (e.g., "on behalf of…"); Named in acknowledgements section; Not applicable: Patient/public partners elected not to be acknowledged; Other (please specify); None of the above
2. Were PPI partners remunerated beyond expenses? Response options: Yes; No; Don't know (please explain)

3. Were PPI partners reimbursed for expenses incurred? Response options: Yes, always; Yes, sometimes; No; Don't know; Not applicable – no expenses were incurred by patient and public partners; Other (please specify)

This study was approved by the Ottawa Health Science Network Research Ethics Board (Reference number: 20210684-01H). In addition, both PPI partners reviewed the main study protocol and provided feedback on the process and survey content. Both patient partners have reviewed the present manuscript and provided critical feedback. The study is reported in accordance with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (Supplementary Material S2) and the GRIPP2-SF (Supplementary Material S3).

Data curation and analysis

Survey data were exported from SurveyMonkey into a spreadsheet using Airtable [32]. Participant characteristics and responses about PPI were summarised using descriptive statistics (frequencies and percentages). All survey responses were analysed regardless of completeness. Most survey items were closed-ended, but many allowed respondents to select "Other" and elaborate in a text box. When the 'Other' category was selected, the open text provided was independently reviewed by two members of the team and coded using a thematic analysis approach, in which data are coded inductively and iteratively with themes generated based on the data, as opposed to coding structures developed *a priori* [33]. The team members subsequently met to discuss coding and come to consensus on the coding scheme. Disagreements were resolved by discussion. Based on the open text responses to the 'Other' category we created two additional categories for the question about recognition (question 1 above): 'Acknowledged in the body of the manuscript' and 'Co-authors on/acknowledged in ancillary research material' as well as a category of 'Unsure or unclear'. In addition, we explored how many respondents had indicated combinations of each support (recognition -authorship or acknowledgement, remuneration, or reimbursement). To facilitate this analysis, we dichotomised responses to yes versus any other response for all three questions (with yes referring to authorship, acknowledgement or both for the question about recognition), thus creating eight permutations.

Results

A total of 3163 unique corresponding authors were invited to complete the survey. Of these, 508 emails were undeliverable and 70 did not receive emails as they had opted out of being contacted by SurveyMonkey. Of the delivered invitations, 710/2585 (27%) responded, with 334/710 (47%) indicating that they had engaged with PPI partners within the trial. Demographic characteristics of respondents who had engaged with PPI partners are shown in Table 2. The number of responses by year of publication of the main trial report is provided in the Supplementary Table S4. In the remainder of the paper, we focus on the responses from these 334 individuals.

Most participants identified as female (173, 60%), white (256, 90%) and late career researchers (203, 69%). The highest proportions of respondents were based in the USA (103, 36%) or UK (81, 28%). Respondents were largely experienced with PPI, with 189 (64%) indicating they had over 10 years PPI experience. The number of respondents increased by year of trial publication (Supplementary Table S4).

Recognition through authorship or acknowledgement

Three hundred respondents completed the question regarding PPI recognition through acknowledgement or co-authorship. Of these, 194 respondents indicated some form of authorship or acknowledgment in the manuscript or within other ancillary research materials (65%). These included papers on study design where patient partners were co-authors, as well as theses, presentations, and reports.

In over a quarter of responses, patient and public partners were reported as being included as authors, either as individual authors (59, 20%) or as part of a group authorship (19, 6%). However, the most common form of recognition was acknowledgement of PPI partners in a specific acknowledgement section (154, 51%), although acknowledgment in the main body of the text (9, 3%) or in other publications or material (5, 2%) was also noted. Acknowledgements were reported to vary, with some specifically naming PPI partners while others reported acknowledgement was to a generic group or providing general thanks to PPI partners. In 35 responses (12%), it was indicated that patient and public partners elected not to be acknowledged. However, 70 respondents (23%) indicated that PPI partners were not acknowledged or listed as co-authors (Table 3). We did not see any indication of a trend over time based on visual inspection (see Supplementary Material S5)

Remuneration of PPI partners

Three hundred respondents completed the question regarding the remuneration of PPI partners. Of these, 132 respondents (44%) indicated that they provided some form of remuneration (e.g., cash salary, vouchers, honoraria). Some respondents provided additional comments using the option of 'Don't know (please explain)' and noted that there could be varied remuneration within studies, with some PPI partners remunerated while others were not. For example, representatives of community

Table 2 Respondent characteristics (*N* = 334)

Item	N (valid %)
Trial population (self-report)	
Children (< 18 years) only	71 (21.3%)
Older adults (> 65 years) only	46 (13.8%)
Neither of the above	217 (65%)
Region of Residence*	
USA	103 (35.8%)
UK	81 (28.1%)
Non-UK Europe	62 (21.5%)
Australia or New Zealand	35 (12.2%)
Canada	13 (4.5%)
Other	6 (2.1%)
Missing	46
Gender	
Male	114 (39.7%)
Female	173 (60.3%)
Prefer not to disclose or missing	47
Age	
25–35 years	6 (2.0%)
36–45 years	49 (16.7%)
46–55 years	84 (28.6%)
56–65 years	94 (32.0%)
> 65 years	61 (20.7%)
Missing	40
Racial or ethnic group*	
White	256 (89.5%)
South Asian (Indian, Pakistani, Sri Lankan)	13 (4.5%)
Chinese	3 (1.0%)
Black	6 (2.1%)
Latin American/Hispanic	4 (1.4%)
Arab	1 (0.3%)
West Asian (Iranian, Afghan)	1 (0.3%)
Korean	1 (0.3%)
Japanese	1 (0.3%)
Other (specified text)	2 (0.7%)
Prefer not to disclose or missing	48
Stage of research career	
Early career researcher (within 5 years of first academic appointment)	13 (4.4%)
Mid-career researcher (6–15 years since first academic appointment)	67 (22.7%)
Late career researcher (> 15 years since first academic appointment)	203 (68.8%)
Retired or Professor Emeritus	8 (2.7%)
Other (e.g., no academic appointment)	4 (1.4%)
Missing	39
Reported years of PPI experience	
1–3 years	12 (4.1%)
4–10 years	95 (32.1%)
> 10 years	189 (63.9%)
Missing	38

** Multiple selections allowed*

Table 3 Details of recognition, remuneration, and reimbursement

Item	Frequency (valid %)
How were PPI partners acknowledged in the manuscript or other materials?¥	
Named as individual co-authors	59 (20%)
Included in group authorship	19 (6%)
Named in the acknowledgement section	154 (51%)
Acknowledged in the body of the manuscript§	9 (3%)
Co-authors on/acknowledged in ancillary research material§	5 (2%)
Not applicable: patient or public partners elected not to be acknowledged	35 (12%)
Unsure or unclear	5 (2%)
None of the above	70 (23%)
No answer/missing	34
Were PPI partners remunerated (e.g., cash, vouchers, honoraria) for their involvement?	
Yes	132 (44%)
No	158 (53%)
I don't know/Unclear	10 (3%)
No answer/missing	34
Were PPI partners reimbursed for out-of-pocket expenses related to their involvement?	
Yes (i.e., always, sometimes)	186 (61%)
No	73 (24%)
Not applicable (i.e., no expenses were incurred by patient and public partners)	35 (12%)
I don't know	9 (3%)
No answer/missing	31

¥ does not sum to 100% as multiple selections possible. § indicates categories developed post-hoc upon review of open responses in 'other' category.

organisations may be remunerated but partners representing a school may not. Again, we did not see any indication of a change in practice over time (see Supplementary Material S5).

PPI partner reimbursement

A total of 303 respondents completed the question regarding reimbursement. Most of these respondents (186, 61%) indicated that PPI partners were reimbursed for expenses incurred, although almost one quarter (73, 24%) indicated that they were not. Thirty-five respondents (12%) indicated that no expenses were incurred by PPI partners, while 9 (3%) were unsure if PPI partners were reimbursed for expenses. While we did not require an explanation to why PPI partners were not reimbursed, some respondents indicated that they had not provided explicit reimbursement as the PPI partners had received an honorarium, which was expected to cover minimal costs that were incurred. Some respondents used the 'Other' category to provide additional details, with examples of reimbursed costs including travel expenses (including parking), or meals. Once more, we did not see

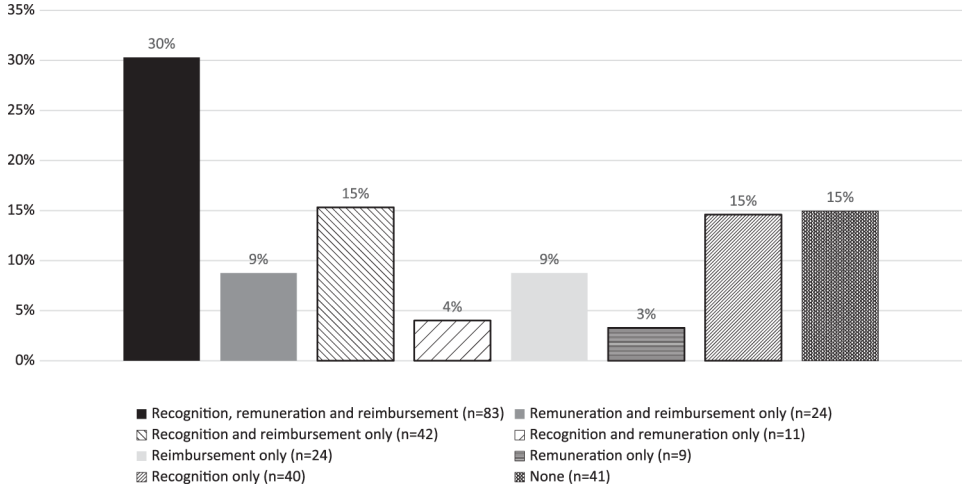

Fig. 1 Reported percentages of recognition, remuneration, reimbursement and combinations of these

any indication of a change in practice over time (see Supplementary Material S5).

Combination of practices

Of 274 respondents who completed all three questions regarding recognition, remuneration and reimbursement (excluding those whose responses were "I don't know"), 83 (30%) indicated that all three were provided to PPI partners, while 41 (15%) indicated that they did not provide recognition (authorship or acknowledgement), remuneration, nor reimbursement. A similar number (40, 15%) provided only recognition without any remuneration or reimbursement, while 57 (21%) provided some form of remuneration or reimbursement but no recognition. A full breakdown of the percentage of respondents for each combination is presented in Fig. 1.

Discussion

Among a cohort of survey respondents who had engaged patients or the public within a published pragmatic trial, less than half reported providing remuneration to PPI partners, and just over half reported reimbursing PPI partners for out-of-pocket expenses related to their involvement. PPI partners were commonly recognised through acknowledgement in publications, with a substantial minority named as co-authors. Almost a third of respondents completing all three questions indicated that they recognised PPI partners through acknowledgement or authorship, provided remuneration, and reimbursed PPI partners.

A strength of our study is that the data were obtained from a survey of corresponding authors as opposed to relying on extracting information from publications. The reporting of remuneration and reimbursement is not a requirement of the Consolidated Standards of Reporting Trials (CONSORT) [34] reporting guideline and, as a consequence, there may be underreporting of remuneration and reimbursement within academic articles. Similarly, there remain challenges to identifying patient authors of manuscripts [35–37]. The self-report nature of our survey removes any interpretation challenges. Finally, our analysis extends the current literature insofar as we also examined combinations of recognition practices, identifying a cohort of respondents who provided no form of remuneration, reimbursement or recognition for PPI partners.

The results must, however, be reviewed in light of the study limitations. First, the response rate was low at 27%. While this may not be unexpected given the unsolicited nature of the survey and relatively long window of time for included trials, it has implications with respect to risks of non-response bias. We may have expected a larger proportion of respondents to not have provided any form of recognition, remuneration, or reimbursement, but with a change over time as policies were adopted by funders, especially given that over half of respondents were from the USA and UK and where funders and government agencies support PPI. As such, we must caution as to the generalisability of these findings to the broader population of trialists. Indeed, it is possible that authors more familiar with, or supportive of PPI and associated practices were more likely to respond to the survey request, thus, yielding an over-estimate of the prevalence of any form of recognition, remuneration, or reimbursement. A second limitation is the earlier publication date of some of the included trials: at the time of the survey, it had been almost 10 years since the publication of the earliest trials in the underlying cohort. While we did have a greater proportion of respondents with more recently published trials, the time that had passed since the completion of some trials may have influenced recall. Future research would benefit from a more contemporary

sample which may address limitations of recall error and provide updated data regarding the recognition, remuneration and reimbursement of patient partners in RCTs. Third, our sample is drawn from respondents located in higher income countries. We did not explore where the trials were conducted, and our results may not generalise to trialist experiences in low- or middle-income countries. A final limitation is our decision to dichotomise the responses for our analysis of combined practices. While we excluded those who indicated a response of 'Don't know' it did include cases where expenses were not incurred and thus not reimbursed. As no expenses were reported to be incurred, we do not know whether these respondents would have reimbursed patient partners had they been incurred and as such the combined categories may overestimate the proportion of respondents who would not reimburse in combination with other forms of recognition or remuneration.

Our results do, however, offer new insights into how PPI partners are financially supported and recognised. Less than a fifth of respondents indicated that PPI partners were a named co-author, lower than previous studies which reported a prevalence of almost 50% co-authorship [19, 38]. However, both of those previous reviews targeted PPI as the topic of interest or had a sampling frame that required reference of the GRIPP [17] or GRIPP2 [18] reporting guidelines, and may represent best case scenarios with respect to implementing or reporting aspects of PPI. Indeed, our survey results are closer to those of a review of PPI in cancer research which found that a third of the included studies had patients as co-authors [39], and is higher than the findings of Vanneste et al [20]. which considered trials published between 2015 and 2023 and who found that only around 10% of articles reporting PPI included a PPI co-author. While we did not see a trend over time in terms of our survey respondents indicating recognition, Vanderhout et al., did find an increasing prevalence of PPI partner authors and/or acknowledged patient partners over time [22]. Furthermore, the recently updated 2025 CONSORT [40, 41] and SPIRIT [42] reporting guidelines now recommend reporting PPI activities which may lead to change in practices of reporting for recognition, remuneration and reimbursement of PPI partners. Together these findings may point to variation between study designs or areas of research, and which would merit future study, particularly given changes in reporting recommendations.

In addition, twelve percent of respondents in our survey indicated that PPI partners declined to be acknowledged. While PPI partners wish to feel valued for their contributions to research [43], research also indicates that there may be reluctance because of stigma attached to a health condition or to research in general and that may influence willingness to be involved as patient partners [44, 45], as well as whether an individual wishes to be formally acknowledged [35]. We did not examine our data for any associations between health conditions studied and the forms of recognition and to date there is a lack of research regarding the perspectives of PPI partners on different forms of recognition, including authorship and acknowledgement. More work is needed to understand the value that is placed in authorship or acknowledgement by PPI partners, but also the potential barriers to PPI partner authorship and acknowledgement. In the interim, PPI partners have written guidance for researchers and how the International Committee of Medical Journal Editors' (ICMJE) guidance can be interpreted for patient co-authors [46].

Our survey indicates a much higher prevalence of remuneration than previously reported, with 44% of respondents indicating that PPI partners were financially compensated. This is higher than the 25% of studies identified by Fox et al [19], and 38% reported by Colomer-Lahinguera et al [39]. However, as stated above, reporting of remuneration is not a requirement of any guidelines. Further, while accepting remuneration is a personal choice, it is commonly considered income and may affect financial support or disability payments for PPI partners [47]. As a result, remuneration may be declined by PPI partners. To date there are few other studies to compare with and more empirical research exploring actual practices, together with the barriers and facilitators to providing or accepting remuneration, are needed.

One surprising finding from our survey related to reimbursement for out-of-pocket expenses, with over a fifth of respondents indicating that PPI partners were not reimbursed for expenses incurred through their involvement. This stands in stark contrast to a recent scoping review which identified 67 international guidance and policy documents, all of which recommended reimbursing patient partners for any expenses associated with engagement [47]. PPI partners should not be left out of pocket for their involvement in research. We strongly suggest that researchers proactively consider the costs that may accrue to PPI partners and build these into their study budget to ensure that they have sufficient funds to support PPI partners for their involvement in research [25, 48, 49]. Further, there are a number of PPI compensation tools to support research teams and we advocate that these be actively disseminated and used [49, 50].

Finally, we found that 15% of respondents who answered all three questions regarding recognition, remuneration, and reimbursement, indicated that none of the practices were implemented. While the approaches implemented may be determined by the extent to which expenses were incurred, availability of funding, and even whether PPI partners wish to be acknowledged, it is surprising that such a high proportion provided none of the

recognition options. While studies have begun to explore the ways in which PPI partners are being remunerated or recognised in publications, we have not been able to identify other research that has examined the combination of recognition, remuneration and reimbursement and which may indicate whether particular practices are being adopted in lieu of others.

Conclusions

In conclusion, our results indicate that researchers report that less than a fifth of PPI partners were recognised as co-authors, a substantial minority are provided remuneration, and the majority are reimbursed. It is important that we ensure that PPI partners are not being left out-of-pocket for their involvement in research, as this could create barriers to participation. Researchers need to proactively consider the costs that may accrue to PPI partners and build these into their study budget. There is also a need to better understand the nature of any barriers that research teams and PPI partners face regarding recognition, remuneration, and reimbursement, and to examine these in a holistic manner, in order to develop targeted interventions that will address these barriers.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s40900-025-00796-y.

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

Supplementary Material 5

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Author contributions

MT, CW and JB acquired funding for the study. MT, SN and SV contributed to the conception and design of the work. AH, MS, PN, SV, MT, SN and KC contributed to the acquisition of data. PN, MT, SN and SV contributed to the analysis and interpretation of data. SN wrote the initial version of the manuscript. All of the authors revised the manuscript critically for important intellectual content, gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

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Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study was approved by the Ottawa Health Science Network Research Ethics Board (Reference number: 20,210,684-01 H). All participants provided an implied consent by completing the survey.

Consent for publication

All authors have reviewed the manuscript and consent to publication.

Competing interests

Charles Weijer reports receiving consulting fees from Eli Lilly & Company. Anne Spinewine reports receiving a Mobility Grant from Fondation Mont-Godinne. No other competing interests were declared.

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